

Future Care Capital – Written evidence (LSI0120)

About Us

Future Care Capital is a national charity committed to engaging, educating and involving all generations in the development and delivery of unified health and care provision. Beginning life as the National Nursery Examination Board in 1945, the charity has evolved throughout its 70-year history and we continue to have Her Majesty The Queen as our Royal Patron. We have set out an overarching positive vision for the health and care system in 2030. We want to see a new agreement between the state and public, which sets out a commitment to support the health and care needs of everyone throughout their life. We envisage that this could be achieved through a Care Covenant, which we are developing, to set out a renewed strategic ambition to deliver the best possible outcomes for the public, that are socially and organisationally borderless.

Industrial Strategy

6. Does the strategy contain the right recommendations? What should it contain/what is missing? How will the life sciences strategy interact with the wider industrial strategy, including regional and devolved administration strategies? How will the strategies be coordinated so that they don't operate in 'silos'?

We welcome publication of the *Life Sciences Industrial Strategy*, its emphasis on putting the UK in a world-leading position to take advantage of the health technology trends of the next 20 years, and its aspiration to address a number of challenges as they pertain to the five key themes of science, growth, the NHS, data and skills.

A number of the recommendations echo those made in our own reports:

- *Intelligent Sharing: unleashing the potential of health and care data in the UK to transform outcomes* (July 2017) – www.futurecarecapital.org.uk/wp-content/uploads/2017/07/Full-Report-Unleashing-the-potential-of-health-and-care-data.pdf ; and
- *Securing the future: planning health and care for every generation* (forthcoming – September 2017).

In particular, we welcome recommendations to:

- **Create the Health Advanced Research Programme (HARP)** – establishment of the HARP to tackle large infrastructure projects and high risk 'moonshot programmes' could, for example, support data philanthropy and the National Health and Care Data Donor Bank we've recommended Government explores in greater depth the better to tackle those challenges we face as an ageing population.
- **Reinforce the UK science offer** – increasing the number of clinical trials and change of practice/trials with novel methodology over the next

five years could, for example, support the establishment of what we've termed 'Living Labs' (i.e. private dwellings, a residential care home and/or connected streets involving the deployment of technologies associated with the Internet of Things (IoT) to facilitate data-driven care in community settings – building upon good and emergent practice in Bukchon Living Lab, Seoul and the CityVerve initiative in Manchester). Our discussions with service innovators highlighted a number of challenges associated with existing ethics frameworks and traditional approaches to research, research cycles and new technologies – in particular, where they involve machine learning and Artificial Intelligence. These will need to be resolved to properly transition from 'smart cities' comprised of connected objects, toward connected citizens empowered by smart technologies.

- **Invest in growth and infrastructure** – supporting the growth of life science clusters. We have recommended that the Government examines the scope to incentivise the establishment of health and care data-driven business clusters in vanguard locations. These clusters should also offer skills training to help prepare the future workforce for the increase in demand for data-related job opportunities. This reflects the emergence of area-wide Accountable Care Systems and a focus on population health, and could help position the UK as a world leader in the delivery of data-driven insights in health and care together with commensurate economic benefits.
- **Facilitate NHS collaboration** – in keeping with the spirit of our recommendation to enshrine collective rights and responsibilities for all digital economy stakeholders in a new digital contract, this recommendation could be cemented by invitations to data-driven enterprises to enter into Joint Ventures with any National Health and Care Data Donor Bank – whether such arrangements are premised upon the UK Government taking some kind of stake in new drugs and technologies later rolled out around the world, or involve long-term deals to secure low-cost access to the same, having made use of the Bank's data for R&D purposes. Joint Ventures could then underpin the communication of perceptible benefits accruing to the NHS and Adult Social Care services in the medium to long-term direct to data donors.
- **Improve data collection, handling and deployment** – we recommend cross-sector working to create a culture of data philanthropy in the interests of research and innovation in health and care – the better to build public trust whilst safeguarding individuals. We also recommend Government explores the scope to establish a National Health and Care Data Donor Bank, alongside piloting a range of 'trusted vehicles' (including data cooperatives, data communities and data collaboratives) to suit different risk appetites and organisational requirements. It also seems entirely logical that interoperability between systems handling health and care data should adhere to a set of common standards and use open APIs to facilitate the straightforward electronic exchange of data. Conceptually, this is akin to electrification and, from our perspective, paramount when conjoining health and care.

In addition to those recommendations outlined above, we have called upon Government to explore two related initiatives which we believe could add value to those provided for in the *Life Sciences Industrial Strategy*:

- 1) The development of a gift-aid style scheme which could involve mandating a data philanthropy option in standard terms and conditions of service and encourage individuals to make health and care data donations for related research and innovation.
- 2) The introduction of a dedicated health and care data privacy shield both to build public trust following negotiations with the EU – www.futurecarecapital.org.uk/press_releases/health-data-fears-over-post-brex-it-trade-negotiations/ – and to reflect moves, elsewhere, by governments to better control data flows to nurture the competitive advantage of home-grown enterprises.

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